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ABSTRACT

This document reviews legislative changes in the Social Security Act State Title V programs to improve maternal and child health, including provision of rehabilitative services to children and adolescents eligible for Supplemental Security Income (SSI) and describes how state agencies are serving this population. An introductory section explains the SSI/Disabled Children's Program, the new statutory referral process, state guidance/program regulations (developing individual service plans, providing services, and coordinating with other agencies), and the legacy of SSI/Disabled Children's Programs. The next section focuses on the Maternal and Child Health block grant program including 1981 legislative requirements, 1989 legislative requirements, ongoing responsibility for SSI beneficiaries, the state program role, the role of the Federal Division of Services for Children with Special Health Needs, and block grant performance measures. The third section addresses current provisions of rehabilitative services by Title V programs including the definition of "rehabilitative services", services to help children learn, and services to help young people transition from school to work. A concluding section identifies some future issues. (DB)

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Introduction

In 1935, Congress enacted the Social Security Act that authorized State Title V programs to improve maternal and child health. The legislation created three separate grant programs for crippled children, maternal and child health, and child welfare. Although Congress has amended Title V over the years, the core mission has continued to focus on the health concerns of women and children, including the special needs of children with chronic health conditions and disabilities.

A milestone in Title V history was the 1976 authorization of the Disabled Children's Program [DCP]. This program evolved from Congressional concern that children eligible for Supplemental Security Income [SSI] benefits were not receiving services for their disabling condition. The SSI/DCP model helped some State Title V agencies begin to reshape their programs to provide more than medical services to children with disabilities.

Congress consolidated the State Title V Maternal and Child Health Program and its Crippled Children's Services along with other categorical programs — including SSI/DCP — to create a Maternal and Child Health [MCH] Block Grant in 1981. The Block Grant was designed to allow states to continue their current MCH and Crippled Children programs, but it gave states more flexibility to define what services they chose to offer. However, the legislation specifically stated that Block Grant funds were available for states to provide rehabilitation services for children under age sixteen who qualify for SSI benefits.

The legislative language referring to "crippled children" was changed to "children with special health care needs" [CSHCN] in 1985, demonstrating Congressional interest for states to serve a more inclusive population. In recent years, a definition of the eligible population has evolved to include children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.

Congress made further revisions in the Block Grant in 1989. It did not change the groups of individuals who may qualify for State Title V services, but clarified what services may be provided. Under Federal law, State Title V programs can provide rehabilitation services for SSI-eligible children under age sixteen, but only to the extent that the services are not covered by a state Medicaid program. The law also allows states to provide family-centered, community-based, coordinated care, including care coordination services.

This paper reviews legislative changes in Title V pertaining to the provision of rehabilitative services to SSI-eligible children and young adults under age sixteen and how state agencies are serving this population.

The SSI/Disabled Children's Program

New Statutory Referral Process

Congress enacted the Supplemental Security Income Program in 1972 as Title XVI of the Social Security Act, to replace state-run benefit programs for adults who are disabled or over age sixty-five. At the same time, coverage was extended so children with disabilities could qualify for Federal disability benefits. Four years later, Congress directed the Secretary of Health, Education and Welfare to develop regulations to assess children's eligibility for SSI. This instruction was issued because guidelines had yet to be published for state disability determination agencies to use when evaluating children for the Federal disability program.

Pub. L. No. 94-566. Section 501

In this same 1976 legislation, Congress directed the Social Security Administration [SSA] to refer all SSI-eligible children under age sixteen to a single state agency to assure appropriate services for them and to coordinate with other agencies serving children with disabilities. This provision was developed because it was apparent that SSI-eligible children were receiving only sporadic assistance and Congress wanted states to create a formal referral process to ensure that these children would receive necessary services.

The statutory language acknowledged the expertise of the State Title V/Crippled Children's Services [CCS] Programs and directed states to use it for the referrals unless the Governor determined that another agency was more appropriate. The legislation required an "identifiable unit" within the state agency to develop and administer a plan to provide services for SSI-eligible children. These units were commonly known as the SSI/Disabled Children's Program [SSI/DCP] and they functioned as an integral part of State Title V programs.

It is particularly noteworthy that Congress directed SSA to refer children under age sixteen to the State Title V/CSS agency. The new provision was added to the existing statutory requirement that SSA refer all SSI-eligible individuals over age sixteen to the state vocational rehabilitation agency. This decision partially reflected concern that state vocational rehabilitation agencies had no previous experience serving children with disabilities under age sixteen. In addition, as a result of a concerted effort to educate Congress about the assistance available to families from State Title V agencies and their Crippled Children's Services programs, Congress expressed apprehension about the existing procedure:

S. Rep. No. 94-1265 reprinted at 1976 U.S.C.C. & A.N. 6019

> The provision for vocational rehabilitation services was designed for persons who could be expected to enter or reenter the work force. It has been of limited benefit even to adult SSI beneficiaries and has not been considered appropriate for children. The lack of a provision in the law has meant that children receiving benefits have not been subject to any formal referral process at all. Being without any legislative guidance, the Social Security Administration has not developed procedures for offices to use on a uniform basis.

The Committee concluded that "this haphazard approach provides no assurance that a child ever actually comes into contact with an agency providing services to handicapped and disabled children, or that services are provided on a continuing basis." Congress clearly wanted a national referral procedure to ensure access to services for children with disabilities:

> Many disabled children have conditions which can be improved through **proper medical and rehabilitative services**, especially if the conditions are treated early in life [emphasis added]. The referral of children who have been determined to be disabled could thus be of very great immediate and long-term benefit to the children and families who receive appropriate services. In addition, the procedure could be expected to result in long-range savings for the SSI program, in that some children, at least, would have their conditions satisfactorily treated and would move off the disability rolls instead of receiving payments for their entire lifetime.

S. Rep. No. 94-1265, reprinted at 1976 U.S.C.C. & A.N. 6019-6020

The legislative history reveals that even in 1976, policymakers recognized the need to encourage interagency collaboration:

> The referral of disabled children by the Social Security Administration would also serve as a case finding tool for community agencies serving disabled children and assist them in focusing their services in behalf of these children. Many communities have the capability to help disabled and handicapped children, but are not always able to identify those with the greatest need.

S. Rep. No. 94-1265, reprinted at 1976 & A.N. 6019-6020

Congress required the state plans to address four specific goals:

P.L. 94-566, Section 501, (b)(1)

- Assure counseling for eligible children and their families;
- Establish "individual service plans" [ISPs] for eligible children under age sixteen and refer them promptly to appropriate medical, educational and social services;
- Monitor compliance with individual service plans; and
- Provide medical, social, developmental and rehabilitative services for children under age seven and those who have never attended public school to enhance their ability to benefit from subsequent education or training or their opportunities for self-sufficiency or self-support as an adult.

The creation of SSI/DCP predates the era of early intervention programs now funded by special education in most states. Consequently, the legislation provided a new opportunity to offer services to the youngest children with disabilities who were largely ignored at this time. The age range selected reflected two concerns: (1) a growing awareness

that addressing disabilities in children as early as possible can significantly improve outcomes for them; and (2) a recognition that as the eligible population of SSI-eligible children under age seven and of those who had never attended public school was fairly small, it would not overwhelm designated state agencies. The legislation was enthusiastically supported by program administrators and policymakers who wanted Title V to expand its role beyond paying for medical services into playing a more pro-active role for children with special health care needs by providing or arranging a more comprehensive range of services.

The legislation required SSI/DCP to provide services only for the youngest children and those who had never attended school. Remember that the new special education law enacted in 1975, *P.L. 94-142* — then called the *Education for All Handicapped Children Act* [EHA], required states accepting Federal funds to provide "a free and appropriate education" for all children with disabilities. This landmark legislation [later renamed the *Individuals with Disabilities Education Act*] was passed to stop the widespread failure of public schools to serve students with disabilities appropriately. In many instances, these children simply were not admitted into public schools. When the SSI/DCP was created, there were undoubtedly children of school age who were eligible for SSI who had not yet attended public school.

Conference Committee Report for P.L. 94-566. Reprinted at 1976 U.S.C.C. & A.N. 6046-6047

Congress did not, however, ignore the needs of older SSI-eligible children. The legislation specifically required individual service plans for all children under age sixteen and prompt referral to appropriate "medical, educational and social services." Further, Congress indicated in its conference report that SSI-eligible children ages seven to sixteen should continue to receive assistance through the current "provision of open-ended Federal funding of vocational rehabilitation services provided by the State vocational rehabilitation agency."

P.L. 94-566 Section 501

The needs of SSI-eligible young people over age sixteen were addressed by mandating SSA to refer them for "vocational and rehabilitation services approved under the *Vocational Rehabilitation Act*." Individuals had to accept these services as a condition of continued SSI eligibility unless they could show "good cause" to refuse them.

Congress appropriated $30 million, divided among states based on their population of children under age seven. The allocation specified that up to 10 percent of the funds could be used for counseling, referral, and monitoring services while the remaining funds were designated to provide services for children under age seven and those never attending public school to enhance their ability to benefit from education or training. Although most of the funds were allocated for services, the SSI/DCP was not intended to operate separately from existing programs for these children. Rather, it was designed to help State Title V agencies coordinate and integrate services that were available from other sources to meet the special needs of this population.

State Guidance/Program Regulations

The Office of Maternal and Child Health [now the Maternal and Child Health Bureau] published comprehensive interim guidance for state plans to implement their SSI/DCPs in July 1977. The guidance, developed with significant input from state program directors and other Federal agency personnel, was issued to provide preliminary information for states to develop their plan for SSI Disabled Children before the official regulations were prepared.

The Guidance was noteworthy at the time because state programs were unaccustomed to such specificity. However, in its opening paragraphs, the Guidance emphasized the importance attached to the new initiative by MCH:

> This regulation is a significant departure from other Federal and State legislation and regulations in that it requires a **full range of services** be provided including medical, rehabilitative, special educational, and social services [emphasis added].

It explained the new legislative requirement for SSA to refer SSI-eligible children under age sixteen to the agency administering the Crippled Children's Services under Title V unless the Governor selected another state agency. It also gave explicit instructions about the requirements to develop a state plan to develop individual service plans for children under age sixteen, to provide medical, social, developmental, and rehabilitative services to children who are under age seven or who have never attended school, and to coordinate services with other agencies for eligible children. The Program Guidance was issued, with minor changes, two years later.

Federal Register, April 18, 1979; codified in the Federal Register at 42 CFR Part 51a

Developing Individual Service Plans

Every child referred by SSA to the Disabled Children's Program was required to have an individual service plan with certain minimum components. The regulations specified that each plan must include certain information, including:

41 CFR 51a. 306(b)(2)

- Statement of the child's medical, educational, developmental, social and rehabilitative needs based on a multidisciplinary evaluation of the child;
- Statement of specific short-term and long-term objectives for meeting the child's medical, educational, social, developmental and rehabilitative needs;
- Description of major activities used to reach each objective, including starting dates and, to the extent possible, an estimate of the duration and frequency of each activity; and
- Statement of the anticipated outcomes for each activity.

41 CFR 51a. 306(c)

The state plan was expected to have a procedure to refer children promptly to appropriate medical, educational, rehabilitative, and social services.

42 CFR 51a. 306(b)(3)

Individual service plans were expected to include, if appropriate, parts of other plans developed for the child by Crippled Children's Services, special education, Developmental Disabilities Services, vocational rehabilitation, Medicaid, community mental health centers, and Head Start.

Providing Services

As noted above, the legislation created separate responsibilities for different age groups of SSI-eligible children. Given the special concern about children under age seven, Congress required the state agencies to provide this age group with "medical, social, developmental and rehabilitation services" either directly or through contractual arrangements. Officials at MCH believed that the new legislation provided an opportunity to expand services at the community level for the youngest children who were not yet enrolled in public school. The intent was to provide a range of services that together "insure a comprehensive continuum of care" for the youngest children with disabilities.

The regulations indicated that Congress wanted a full range of services provided because they could "reasonably promise to improve the child's ability to benefit from subsequent education or training, or otherwise improve his opportunities for self-sufficiency or self-support as an adult."

The Guidance directed states to include preventive, diagnostic and treatment services from a wide range of providers and specialists such as:

- Hospitals, clinics, institutions, schools, and other facilities;
- Physicians and dentists;
- Nurses;
- Child development specialists;
- Psychologists;
- Occupational and physical therapists;
- Optometrists;
- Speech and hearing specialists;
- Special educators;
- Rehabilitation counselors;
- Social workers; and
- Other personnel whose services are needed for the treatment and care of disabled children.

The final regulations directed state agencies to provide directly or by contract a wide range of services. Among the services listed were the following:

42 CFR 51a. 307(d)

- Preventive diagnostic and treatment services of a physician and as appropriate, physician extenders;
- Inpatient and outpatient hospital services;
- Dental services;
- Nursing services;
- Home health services;
- Social services;
- Rehabilitative services, including long-term and short-term physical and occupational therapy;
- Speech and hearing services;
- Vision services;
- Child development services;
- Mental health services;
- Counseling services, including rehabilitative, developmental, social, occupational, and educational counseling;
- Pharmaceutical services, including provision of drugs;
- Medical devices and related services;
- Transportation services needed to carry out the individual care plan; and
- Other services necessary to assist in carrying out the individual service plan.

The Guidance explained that services were to be provided only when they "reasonably promise to enhance" the child's ability to benefit from education or training or to become self-sufficient. However, the Office of Maternal and Child Health interpreted this phrase very broadly and instructed State Title V agencies to offer services to all children under age seven who were referred. The Federal agency believed that its interpretation was supported by the legislative history that "recognizes the uncertainty of evaluations of a child under seven and, therefore, focuses on improving the child's condition and benefiting the child."

1977 SSI/DCP Guidelines, Part IVC-5

1977 SSI/DCP Guidelines, Part IVC-7

The same services, however, were required for children of any age who were referred and had never attended public school. The Guidance clearly stated that this was required "provided it prepares them to benefit from subsequent education or training, or otherwise enhances their opportunities for self-sufficiency or self-support as an adult." Except in cases involving children who never attended school, SSI/DCP direct services funding generally ceased upon children's seventh birthday. Services and case management could — and often did — continue for a reasonable time if there was an expectation that children could achieve their objectives.

Coordinating with Other Agencies

42 CFR 51a. 309

Recognizing the need to maximize state resources, the regulations required the state plan to assure that cooperative agreements were made with all appropriate agencies serving children with disabilities. The purpose of the cooperative agreements was to "assure that services under the plan are coordinated with all principal public and private State and local agencies providing services to disabled children and that all reasonable efforts are made to use existing services and to obtain financial support from these agencies."

The Guidance instructed State Title V agencies to use their plans to establish interagency agreements to coordinate medical, educational, social, developmental, and rehabilitative services. In the regulations, the following agencies were listed:

- Developmental disabilities;
- Vocational rehabilitation;
- Medical assistance, including the Early and Periodic Screening, Diagnosis and Treatment [EPSDT] Program;
- Social services;
- Special education;
- Head Start;
- Maternal and Child Health and Crippled Children's Services;
- Mental health;
- Mental retardation; and
- Services for the blind.

State Title V programs were monitored to check the effectiveness of their coordination as well as the quality of direct services provided.

Legacy of SSI/Disabled Children's Programs

MCH officials recall that many State Title V agencies were genuinely interested in their Disabled Children's Programs. Some welcomed the new Federal funding that was available to provide case management for all children under age sixteen and to provide or arrange services for children under age seven. The new funds helped some State Title V agencies begin reshaping their mission beyond the traditional Crippled Children's Services "medical model" into a program that offered a more comprehensive array of services designed to help children maximize their potential and begin planning for a successful transition to adulthood.

The 1976 SSI/DCP legislation, together with the program guidance and regulations, set the stage for later bills enacted by Congress to address the special needs of children with disabilities and chronic health conditions. It was the first Federal law to establish interagency collaboration as a goal for this population of children. Congress established an important precedent by directing State Title V agencies to coordinate medical, educational, social, developmental, and rehabilitative services for these children. By recognizing the importance of providing a full range of services for SSI-eligible children, this early legislation served as a prototype for a comprehensive program serving all children with special health care needs.

The Maternal and Child Health Block Grant

1981 Legislative Requirements

Congress significantly amended Title V in its *Omnibus Budget Reconciliation Act of 1981 [Pub. L. No. 97-35*, commonly called *OBRA 1981*]. This law consolidated the Title V Maternal and Child Health Program and its Crippled Children's Services along with other categorical programs — including SSI/DCP — to create a new Maternal and Child Health [MCH] Block Grant. The Block Grant reduced the Federal government's oversight role for MCH programs and gave states more flexibility to define their own services.

When authorizing Federal funds for the new Block Grant, Congress established four goals that each state may use for its maternal and child health programs. One goal was "to provide rehabilitation services for blind and disabled individuals under the age of sixteen receiving benefits under title XVI of this Act."

Pub. L. No. 97-35, Section 501(a)(3)

Although the SSI/DCP regulations were rescinded by the Block Grant, this new provision specifically authorized use of Federal funds by states to provide rehabilitation services for SSI-eligible children under age sixteen. By adding this provision, Congress acknowledged that state agencies could allocate their Federal funds to continue assistance to the SSI/DCP population who were previously served through categorical fund-

ing. There is no specific discussion about the words "rehabilitation services" in the legislative history. However, by including the provision of these services as a goal, Congress recognized that MCH programs might continue to perform this function.

Senate Finance Committee Report for P.L. 97-35, reprinted at 1981 U.S.C.C. & A.N. 751

The legislative history indicates that the purpose of the Block Grant was to help states achieve greater efficiency by combining related health care programs for mothers and children. Congress believed that consolidating various programs permitted states "to use their Title V funds for any of the services and activities that were previously authorized under the separate programs being merged. The Block Grant approach leaves the States free to determine the specific MCH activities to be funded and how to carry out individual State programs." When it consolidated SSI/DCP with the Crippled's Children's Services programs, Congress may have hoped that State Title V agencies would continue to address the special needs of SSI-eligible children and help them maximize their current and future potential as early as possible. However, there is no explicit instruction to the states to do so.

Under *OBRA* 1981, Federal funding was allocated proportionately based on each state's relative share of funds received in that fiscal year under programs consolidated into the new MCH Block Grant. States were required to match every four dollars of Federal funds with three dollars of state funds. Congress directed that a "substantial portion" of all funds be used to provide health services to mothers and children, with special consideration given to projects previously funded by Title V, and a "reasonable proportion" used for other purposes, including the provision of rehabilitative services for the SSI-eligible population under age sixteen.

By creating the Federal Block Grant, Congress gave states the discretion to decide the fate of their Disabled Children's Programs and the functions they performed. Some State Title V programs reported that they continued to receive referrals from SSA under the Title XVI requirements that remain in effect. Most states did not maintain a separate unit for this population but continued to provide or purchase medical and/or case management services for SSI-eligible children as part of their regular agency procedures.

1989 Legislative Requirements

In its Omnibus Budget Reconciliation Act of 1989, Congress again amended Title V and redefined the mission of the Children with Special Health Care Needs [CSHCN] Program.

The Title V legislation allows state CSHCN programs to:

42 U.S.C. 701(a)(1)(C)

- Provide rehabilitation services for blind and disabled individuals under the age of sixteen receiving benefits under Title XVI to the extent medical assistance for such services is not provided under Title XIX;

- Provide and promote family-centered, community-based, coordinated care (including care coordination services) for children with special health care needs; and

42 U.S.C. 701(b)(3)

- Facilitate the development of community-based systems of services for such children and their families.

42 U.S.C. 701(a)(1)(D)

Congress continued authorization for states to provide rehabilitation services for SSI-eligible children under age sixteen, but added an important clarification. Now State Title V agencies can provide these services only "to the extent" that Medicaid does not cover them. This provision was added to clarify the "payor of last resort" issue for State Title V programs and was particularly timely because Congress expanded the array of services that eligible children can receive through Medicaid. In its report, the Conference Committee explained the rationale for this significant legislative change:

> Because MCH Block Grant dollars are in such short supply, the Committee believes it is inappropriate for Title V to pay for rehabilitation services for this population if such services are already provided under a State's Medicaid plan. If, however, a State's Medicaid plan does not provide coverage for these services, the Title V program may be the most appropriate source for assistance. Under the Committee's bill, States are authorized to provide such assistance only in these limited circumstances.

H. Rep. 101-247 reprinted at 1989 U.S.C.C. & A.N. 223; Recommendations of House Committee adopted by Conference Committee, reprinted at 1989 U.S.C.C. & A.N. 31093.

By specifying that states may provide family-centered, community-based, coordinated care for children with special health care needs, Congress indicated its concern for this population of children. To help ensure that a full array of services are available, Congress allows CSHCN programs to provide care coordination, defined as "services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families."

By amending the Title V statute to include the provision of "care coordination," Congress endorsed the concept that children with special health care needs and their families can benefit from a full array of services. This concept can be traced back to the early days of the Disabled Children's Program and the initial efforts to move beyond a "medical model" to a program that provides or arranges a full continuum of services for children with disabilities and chronic health conditions and their families.

42 U.S.C. 701(b)(3)

Ongoing Responsibility for SSI Child Beneficiaries

State Program Role

By providing care coordination, State Title V agencies can help ensure that SSI-eligible children and young adults have access to the rehabilitative and other services that they need. State Title V agencies can play a critical role by helping to maximize available resources and collaborate with other child-serving agencies to ensure that the medical, social, educational, developmental, and rehabilitative needs of the target population are met.

Federal Role of Division of Services for Children with Special Health Needs

Over the years, the Division of Services for Children with Special Health Needs has provided technical assistance and support to State Title V programs to help them meet their obligations to SSI-eligible children and youth.

A number of changes affecting the children's SSI and State Title V programs that occurred in 1989 and 1990 placed CSHCN programs in a pivotal role to help an expanded population of children with disabilities access a broad array of needed services:

- The U.S. Supreme Court ruled in *Sullivan v. Zebley* that the disability evaluation process for the children's SSI program must consider functional limitations. Previously children were evaluated only on medical evidence. This landmark decision allowed children who were previously denied benefits to be reevaluated and, as a result, tens of thousands of children qualified.

- The Social Security Administration [SSA] issued new regulations for evaluating childhood mental impairments that require assessment of functional limitations.

- Congress mandated SSA to conduct an outreach program to locate families whose children might be eligible for SSI benefits.

- Congress allowed State Title V programs to provide family-centered, community-based, coordinated care for children with special health care needs, including SSI-eligible children under *OBRA 1989*. The State Title V/CSHCN programs are permitted to provide rehabilitation services to SSI child beneficiaries, but only to the extent that they are not covered by Title XIX (Medicaid).

- Congress expanded the scope of services states must provide Medicaid-eligible children through its Early and Periodic Screening, Diagnosis and Treatment [EPSDT] program.

Responding to these changes, the Federal SSI/CSHCN Work Group was formed in May 1990 to support efforts by SSA, MCHB, State Title V programs and state Disability Determination Service [DDS] agencies. For three years, the Work Group focused on ways to improve outreach to eligible children and linkages among different agencies serving children with disabilities. In its second phase (1993-1997), the Work Group convened a series of state or multistate regional meetings across the country to educate interagency state teams about changes in the children's SSI program and to improve interagency coordination and services for SSI-eligible children.

Ten meetings, held over this four year period, provided the opportunity for forty-nine states to participate. States sent teams of representatives from SSA, DDS, State Title V/CSHCN, vocational rehabilitation, Medicaid, Education Department and Part H (now Part C) programs so they could develop state-specific actions plans for collaborative activities. The Work Group activities and state/regional meetings were coordinated and supported through the Institute for Child Health Policy under grants from the MCHB.

Block Grant Performance Measures

Congress passed the Government Performance and Results Act of 1993 [P.L. 103-62] to help ensure greater accountability from Federal agencies. Each Federal agency must establish performance measures, to include as part of their budgetary process, that create specific outcomes to monitor the agency's service for its target population.

When the Federal legislation passed, the MCHB was already developing a Title V Information System to track state program performance. To help State Title V programs comply with the new Federal requirements, a special Work Group met with the Bureau in 1997 to support development of relevant questions for the state Maternal and Child Health Block Grant application that can track services for children with special health care needs. The Work Group included representatives from the State Title V CSHCN Programs, the Association of Maternal and Child Health Programs (AMCHP), the American Academy of Pediatrics, Family Voices, Institute for Child Health Policy, National Association of Childrens' Hospitals, and other CSHCN policy leaders.

Based on the Work Group's recommendations, some performance measures were included that will assess states' performance for children with special health care needs. Two of the eighteen national core performance measures are particularly important for the SSI population:

- The percent of state SSI beneficiaries less than sixteen years old receiving rehabilitative services from the State CSHCN Program;

- The degree to which the state CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.

In its Guidance for the Block Grant application, the MCHB explained the significance of each of these performance measures:

- **Rehabilitative Services**. Title V legislative requirements mandate the provision of rehabilitative services for blind and disabled individuals under the age of sixteen receiving benefits under the SSI program to the extent medical assistance for such services is not provided by Medicaid. The Title V responsibility for providing and promoting family-centered, community-based care serves as a basis for states to establish a policy whereby all SSI disabled children are eligible to participate in or benefit from the State Title V CSHCN Program.

MCHB Block Grant Guidance, 12/22/97, page 104.

- **Payment for Specialty and Subspecialty Services**. The State CSHCN Programs have traditionally provided and/or finance specialty and subspecialty care which is otherwise not accessible or available to subpopulations and has functioned as the payor of last resort for medical, habilitative and rehabilitative services, and equipment and assistive technology for segments of the CSHCN population. The legislation also mandates the direct involvement of State CSHCN Programs in the design and implementation of care coordination programs and the actual provision of care coordination services, as determined by the States. This function is particularly critical given current changes in coverage resulting from managed care arrangements. SSI changes will, at least temporarily, cause many children to lose Medicaid benefits and other welfare reform measures, which are expected to increase these numbers.

http://cshcnleaders.ichp.edu

MCHB Block Grant Guidance, 12/22/97, page 105.

Performance measure data was collected from state programs in the fall 1998. Staff at the National Center for Education in Maternal and Child Health are analyzing the data and are posting their findings on their Web site.

www.ncemch.org

Current Provision of Rehabilitative Services by State Title V Programs

A survey was conducted by the U.S. General Accounting Office and the Institute for Child Health Policy in spring 1998 to obtain information about the current provision of rehabilitative activities by State Title V/CSHCN Programs. The survey asked programs to answer three questions regarding their rehabilitative services for children under age sixteen who receive SSI:

- What is your State Title V/CSHCN Program definition of "rehabilitative services" for these children?
- Does the definition cover services to help them learn effectively?
- Does the definition cover services to help them transition from school to the work force?

An analysis of the state responses follows which indicates wide variation among their interpretations of their responsibilities to SSI-eligible children.

Definition of Rehabilitative Services

Range of Definitions

Roughly one-half of the states (23 of 46 responses) have a specific definition of rehabilitative services for this population although they vary considerably. Among them, one-half (12 of 23 responses) broadly define "rehabilitation" to cover a wide range of activities or a philosophy that emphasizes maintaining or improving children's functioning:

- Vocational, social, psychological, medical, and educational rehabilitation services to train or retrain individuals disabled by disease or injury to the highest possible level of functional ability;
- Three levels of services to: restore children to normal after disability, disease, or injury; or to maintain functioning; or to preserve minimal functioning to sustain life;
- Social work services to meet beneficiary's medical, educational, and social habilitation needs through outreach, assessment, planning, information/referral/linkage, case management, and follow-along services with family and others involved in child's care;
- Services to maximize potential of children with special needs to support activities of daily living, develop coping skills, and link families to community, resources, programs, and services;
- Services to improve child's ability to benefit from subsequent education or training or otherwise improve his/her opportunities for self-sufficiency or self-support as an adult;
- Medical and therapeutic services that promote optimal development of individual child;
- Services to maintain or improve functioning;
- Services directed at specific outcomes of empowerment, care assistance, stress education, and access to medical supports;
- Services requested by managing physicians that includes both rehabilitation and therapy for maintenance;
- Medical and ancillary services to treat specific diagnosis and as requested by the family.

The remaining states (11 of 23 responses) have a more traditional medical definition that includes a list of covered services:

- Medical, surgical, therapy and coordination of these services;
- Occupational, physical, speech therapies; provision of appliances, prostheses, braces and adaptive equipment; audiological evaluation, hearing aids, and repairs;
- Medical, surgical, corrective, and other services and care for diagnosis, clinical services, hospitalization, and aftercare;
- Services associated with medically eligible conditions;
- Occupational, physical, and speech therapies; durable medical prosthetics and surgical interventions related to the eligible condition;
- Occupational, physical, and speech therapy and durable medical equipment;
- Occupational, physical, and speech/language therapy and audiology;
- Outpatient speech, occupational, and physical therapy, and durable medical equipment and supplies not covered by Medicaid;
- Hospitalization, physicians' services, special therapies, and durable medical equipment;
- Occupational, physical, and speech therapy and some equipment communication devices;
- Treatment services directly related to covered condition in state plan for children's specialty services.

Two programs indicated that they focus on habilitative — not rehabilitative — services.

One program described its function providing rehabilitative care through both direct service and collaboration with agencies such as Part C (early intervention programs funded through IDEA), special education, and vocational rehabilitation.

Three programs indicated that they do not have a formal definition of rehabilitative services at this time, although two of them were either developing or reviewing it.

No Separate Definitions

Five states do not separately define rehabilitative services for this population of children because they provide the same services to all eligible children, regardless of their SSI status.

Eleven State Title V/CSHCN Programs believe that the Title XIX (Medicaid) agency must cover the required rehabilitative services as part of children's medical needs. Consequently, they do not provide rehabilitative services to avoid duplicating the effort. However, several programs acknowledge the gap they must fill by:

- Covering medically necessary services for the medically eligible condition;
- Serving as "payor of last resort" if Medicaid or other insurance does not provide the services; or
- Providing care coordination and advocacy services if Medicaid denies treatment or durable medical equipment that is medically necessary for a specific child.

One program listed the kinds of services that it covers as "payor of last resort" including: medical rehabilitative specialized therapy, home therapy, medications, laboratory, radiology, nutritional supplements, disposable supplies, patient/family education, and social services.

Services to Help Children Learn

The majority of State Title V/CSHCN Programs (27 of 43 responses) do ***not*** include services to help children learn effectively as part of their definition of "rehabilitative services." In one program, care coordinators will facilitate IEP discussions when requested.

About one-third of the programs (16 of 43 responses) believe these services are part of their defined rehabilitative services although the survey does not indicate how they define them. A few examples were provided:

- The assistance is limited to providing a diagnosis or education evaluations. One of these programs clearly states that it will not duplicate services that should be available from education;
- The assistance includes services for school-age children that are identified under an individual education plan;
- The program response will depend on the service, using the example that they provide hearing aids, but not computers.

One program believes these services are covered under special education requirements so it does not provide any assistance.

Services to Help Young People Make the Transition from School to Work

The majority of State Title V/CSHCN Programs (28 of 43 responses) do not include services to help young people make the transition from school to work as part of their defined "rehabilitative services."

About one-third of the programs (15 of 43 responses) believe they provide this assistance as part of their rehabilitative services although the survey does not indicate how they define transition services. A few examples were provided:

- Care coordinators facilitate the referral to the appropriate agencies;
- CSHCN provides transition services that are identified in the childrens' individual education plans;
- The program response will depend on the service, using the example that mobility aids like power wheelchairs are provided, but they may not be able to provide the full range of assistance that young people may need.

Two programs believe these services are covered under special education requirements including through vocational rehabilitation.

Only one program cited its role in the medical transition from pediatric to adult care, which it defines as including referral to the state vocational rehabilitation program.

Future Issues to Address

The survey indicates that state programs do not have a uniform response to their responsibility to provide rehabilitative services, as evidenced by the variation in the type and scope of assistance provided. State programs also differ in their opinions about what services State Title V/CSHCN programs should finance and when the responsibility rests with another agency. These responses raise critical issues for policymakers to address about the future of CSHCN programs:

- Are programs meeting their legislative mandate to provide rehabilitative services to SSI-eligible children under age sixteen?

- Are programs broadly defining rehabilitative services or do they only list available medical interventions?

- Do programs make a distinction between "rehabilitative" and "habilitative" services? If so, which services are provided?

- Do programs provide direct services and also collaborate with other appropriate child-serving agencies to ensure access to services for this population of children? If so, how do they balance these two roles?

- What services do programs finance for this population of children? How do State Title V agencies coordinate and collaborate with such other agencies serving children with disabilities as Medicaid, education, vocational rehabilitation, and mental health/mental retardation agencies? How do these agencies decide who will finance such different services as medical assistance, services to help children succeed in school, and transition services from school to work?

Survey available at info@ichp.edu

Notes

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